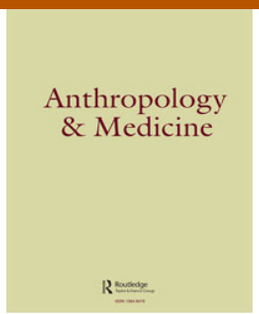

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# The justification of studies in genetic epidemiology – political scaling in China Medical City

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**ABSTRACT**

Genetic epidemiology examines the role of genetic factors in determining health and disease in families and in populations to help addressing health problems in a responsible manner. This paper uses a case study of genetic epidemiology in Taizhou, China, to explore ways in which anthropology can contribute to the validation of studies in genetic epidemiology. It does so, first, by identifying potential overgeneralizations of data, often due to mismatching scale and, second, by examining it's embedding in political, historical and local contexts. The example of the longitudinal cohort study in Taizhou illustrates dimensions of such 'political scaling'.

Political scaling is a notion used here to refer to the effects of scaling biases in relation to the justification of research in terms of relevance, reach and research ethics. The justification of a project on genetic epidemiology involves presenting a maximum of benefits and a minimum of burden for the population. To facilitate the delineation of political scaling, an analytical distinction between donating and benefiting communities was made using the notions of 'scaling of relevance', 'scaling of reach' and 'scaling of ethics'. Political scaling results at least partly from factors external to research. By situating political scaling in the context of historical, political and local discourses, anthropologists can play a complementary role in genetic epidemiology.

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China; epidemiology; political scaling; genetics; biosecurity

## 1. Introduction

After the realization that most diseases are not of a Mendelian nature but are influenced by multiple genes, epigenetic processes and the human environment, genetic studies on the relation between health- and social-related human behaviour and its environment became widespread (Nitsch et al. 2006). Genetic biobanks, including long-term genetic cohort studies, serve to facilitate studies of genetic epidemiology (GE), a scientific field which emerged in the 1980s, including in China (Sung 2009). GE examines the role of genetic factors in determining health and disease in families and in populations. In epidemiological cohort studies of genetic populations, genetic and environmental factors form the basis for defining statistical links between biology and society. Such links are hoped to

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give rise to insights into genetic and environmental factors in disease aetiology (Burton, Tobin, and Hopper 2005; Campbell and Anderson 2008). Focusing on the genetic component of a disease and the relative contribution of genes and environment (Dorak 2015), the selection of sample populations for a particular condition is crucial to research outcomes. And as GE seeks to conduct statistical and quantitative analysis of how genetics work in large groups (Khoury, Beaty and Cohen 1993), it is crucial for GE to understand how generalizations over larger populations are derived from sample populations.

There have been controversies around the validity of epidemiological research data and the ethics of genetic biobanks. Thus, anthropologists have argued that, as diseases have their own sociocultural histories, epidemiological research should be sensitive to these when discussing the validity of research data (Inhorn 1995; Helman 1994; Trostle and Sommerveld 1996**;** Trostle 2005). While other debates have focused on the unethical use of genetic data, associated with the risks of storing genetic data and information in biobanks, and anxieties about 'genetic discrimination' (Duster 2003; Lock 1994; Lewontin 2001; Tutton 2010; Sleeboom-Faulkner 2009, 2010), in this article, I would like to focus on issues related to the ways in which GE studies, including banking activities, justify research in terms of the reach, relevance and ethics of research outcomes.

In 2007, I first heard about the ethical controversy around the Taizhou biobanking project in China Medical City (CMC) from BBC correspondent Poppy Toland. The controversy pertained to the method and speed of collecting sensitive genetic and epidemiological research data from the population of Taizhou. CMC has various star projects that have received wide media attention, one of which is the Taizhou biobank, set up in 2006 and conceived by Huang Jinlin, its former CEO. The biobank was initially managed by the American company Berkeley Biotech, but started collaborating with a prominent Chinese university, X, soon after. It was registered as a Chinese company in April 2007, a move that secured the company RMB 15 m (US$2 m) for the project from CMC, as well as additional US investment (Toland 2007). In June 2007, University X and CMC established the 'Taizhou Cohort Health Research Project' [泰州人群健康追踪研究项目]. Wang Jingsu, deputy director of CMC, announced that:

> Volunteers and sample donors will contribute to what project organisers claim could become the world's largest genetic databank. Launched in June 2007, in October it already holds samples from 10,000 people, only a minute proportion of the *five million* it aims to accumulate over the next decade … This project will improve Taizhou in every respect, whilst also contributing to the development of China. (cited in Toland 2007, *italics are mine*)

In 2008, the project had accumulated over 10,000 samples moving on to surrounding Greater Taizhou City, villages and the city of Taixing. Research co-operation through the Chinese Medicine and Health Academy of Science aimed to set up a large-scale research platform (大型分子流行病研究平台) and a national level large-scale research team (国家级大型分子流行病研究队列) for molecular epidemiology. Having obtained permission from housing committees in different areas within Taizhou to visit residents to ask for their participation, Deputy Director Wang, asserted that CMC collects samples from people on a voluntary basis. This was questioned, however, as compared to the experience of other countries, collecting the genetic data from one-fifth of its five million citizens, in agreement with its five-year plan, would be miraculous. Thus, neighbour Japan had had extreme difficulties finding volunteers for its national cell bank (Masui 2009), and in

Taiwan the biobank venture many regards as a failure due to bioethical issues hampering recruitment (Yang 2007). This issue was not further explored in the press, and the Taizhou biobank received little media attention over the next few years.

When I visited Shenzhen in 2009, however, I happened to attend a presentation of the researchers involved in the Taizhou biobank. The presentation showed that the biobanking project had made a radical turn-around and was now called the 'Taizhou longitudinal cohort study' (TZL). Some of China's most eminent epidemiologists and physical anthropologists presented their research methods and results in an impressive manner, and have since published their data (e.g. Hu et al. 2015; Tang et al. 2015). At the same time, however, I was struck by the major claims the research made on the basis of the research conducted in and around Taizhou: the data generated by the cohort study seemed to be relevant not just to Taizhou, but to geographies of a much larger scale, such as China, Asia and the world. The literature on GE warns against such overgeneralization or overmatching (e.g. Friedman 2004, 111; Trostle 2005, 77). So I decided to examine how the use of scales in this study had come about, and started planning various research visits to Taizhou and the institutes involved in TZL. Using the example of the TZL, this paper explores the notion of political scaling and its role in GE.

### 1.1. Political scaling and its scientific and ethical relevance

The notion of political scaling refers to the effects of scaling biases in relation to the justification of research in terms of the relevance, reach and research ethics in the study of GE. I argue that the justification of a project on GE involves presenting a study in such a way that it shows a maximum of benefits and a minimum of burden for the sample population. To facilitate the delineation of political scaling in the context of project justification, I make a distinction between donating and benefiting communities. The comparison of these two kinds of communities in the context of political scaling may help determine and justify the value of studies in GE. Before this cussing this, I will first refer to anthropological work that focuses on the scaling bias in anthropological argumentation to clarify the notion of political scaling.

In her well-known work, *Partial Connections*, anthropologist Marilyn Strathern showed that rendering a comparison valid is a daunting task for anthropologists: the use of potentially infinite perspectives and the ability to alter magnification gives the observer the sense that any approach is relative or only partial (Strathern 2004, xiv). For this reason, the choice of angle, unit of comparison and value standards are crucial to making a compelling argument. Thus, the mismatch of perspectives and scales explains the failure of cross-cultural comparison in anthropology, and anthropologists have criticized each other for making skewed comparisons. Examples are the comparison of ceremonial exchanges in different geographical locations without recognizing their different functions and settings, or the comparison of phenomena using different scales of magnitude, such as comparing hamlets with towns, so that detail is lost in some cases and overstated in others. This paper, however, is concerned with the generalization of research data over inappropriate units of analysis.

Although a scaling bias can be unintended, it can also be produced on purpose by strategically 'zooming into' variously scaled units of analysis to caste a study in a particular light. However, this paper uses the notion of 'political scaling' to refer to the political

effects of *both intended and unintended scaling biases*. Thus, the *scaling of relevance* refers to the way a GE study claims to be relevant in addressing the problems of a certain community; the *scaling of reach* refers to the ways in which banked epidemiological data from a 'donating community' are claimed to be generalizable, and therefore useful, to a wider 'benefiting community'; and, the *scaling of ethics* refers to the claimed appropriateness of ethical review procedures of one location for a study in a wider or other area. This study will especially focus on representations of 'donating' and 'benefiting' communities. Researchers justify the selection of the communities for sampling genetic and qualitative data both scientifically and in terms of the merits to the 'benefiting communities'. The scaling of a study can indicate the range of a problem, the size of a sample population and the populations over which the research results are generalized. As will be explained in Section 2, studies define target communities from various perspectives (e.g. genetics, epidemiology, demography, sociology, politics, economy, health), and scale the communities at various geographical levels (e.g. village, city, province, national region, nation-state, world region, international institution). Here, the correspondence between the scaling of the research population and that of the benefiting community is crucial to whether the research results are applicable.

To understand the way in which studies define the relevance, reach and ethics of a study, it is important to gain insight into the local understandings and political discourses of research units, research and socio-economic problems, data gathering, generalization and ethical oversight. Thus, whether a study will lead to the catering of local health needs, and the value of a study to populations with a particular genetic make-up, lifestyles and environment, and the ethical organization of the study can be crucial to the justification of the implementation of a project. This is why anthropologists and epidemiologists have argued that, when population-based studies are divorced from community needs, they are thought not to fulfil requirements of 'benefit-sharing' (Hayden 2007; Winickoff 2008; Tutton 2010; Friedman 2004; Beskow and Burke 2009; Trostle 2005), and when research is conducted where there is no indication that the behaviour or phenotypical expression should be prioritized as a subject of study (Porter et al. 2009, 230, 234), it is likely that targets other than the health of the population drive the research, including intellectual curiosity, the desire to partake in international collaborations, reputation and acquiring materials for publication (Sleeboom-Faulkner and Patra 2011; Sleeboom-Faulkner 2016b).

Ethicists regard some research in GE as problematic, as the banking of tissue and blood samples and information of human donors may unnecessarily put the privacy and confidentiality of donor populations at risk (Knoppers 2003; Gottweis and Peterson 2008; Sleeboom-Faulkner 2005, 2007). In the disciplines of international politics, bioethics, the ethics around the use and meaning of informed consent, privacy, autonomy and beneficence, has been seen as a neutral currency between countries negotiating and trading values (Salter and Salter 2007). Systems of bioethical precautions try to address these issues. However, Chinese researchers and scientists elsewhere have questioned the validity of international research ethics (Fan 1999; Tao 2002; Sleeboom-Faulkner 2016a). Such disagreements add to the urgency of understanding the study design of GE research in relation to the main stakeholders in the research, such as governments, scientists themselves, the pharmaceutical industry and the various donating and benefiting populations, and how the research is oriented towards these.

### 1.2. Method

Because claims made in GE cohort studies often underpin decisions regarding research participation, research funding, science policies and public health, I decided to visit research institutes involved in the TZL to enquire about these. In this paper, I focus on the role of political scaling in the misrepresentation of donating and benefiting communities through epistemological mismatches of relevance, reach and ethics. I propose that discursive context forms both a conceptual resource for and a background to political scaling: a resource for conceptualising historical, national and local dimensions of a study in GE, and a 'real' background that justifies a particular project in genetic, medical, financial and security terms. My focus on the qualitative dimensions of GE in this exploratory study means that this paper's discussion is limited to the exploration of political scaling, measured in the ways in which the sample population and research outcomes are claimed to benefit certain communities on the basis of the donations of others. To facilitate this exploration, I conduct an in-depth background examination of a longitudinal cohort study on GE conducted by a group of internationally highly-regarded epidemiologists cum physical anthropologists.

For this study I followed publications based on the TZL, visited the research institutes associated with the TZL, and interviewed the researchers associated with it. In this paper, I mainly concentrate on the group's 2009 study *Rationales, design and recruitment of the Taizhou Longitudinal Study* (RDR, Wang et al. 2009, 223), which is the only TZL publication that focuses exclusively on GE. To gain further insight into the study, I met up with members of the research group in Shenzhen, Taizhou and Shanghai, where I interviewed researchers in groups and separately from 2009 to 2013. I conducted two semi-structured interviews in 2009, and three semi-structured interviews conducted in Taizhou in 2012 and 2013, combined with various visits to biobanks in Taizhou. To deepen insight into the historical and national discursive embedding of the TZL research, I have drawn on literature and archival studies conducted over two decades regarding the notion of race, genetics and the socialist state (referred to in the text). To avoid drawing attention to persons central to the study, I have refrained from using the names of interviewees and have not indicated their positions; neither have I named the university that figures in the collaborative study.

By outlining some of these political and discursive contexts of GE in Taizhou, I hope to gain insight into how political scaling links the local with wider geographical scales and justifies the project in terms of donating and benefiting communities. In Section 2, I outline the political dimension of the presentation of relevance, reach and ethics through the scaling of donating and benefiting communities, and show how the Taizhou cohort study deals with the critical eye of the international community, national and local governments and various publics in interviews and in research publications. Section 3 outlines how anthropologist can highlight and contextualize political scaling in terms of the local, historical and national discourses and pressures that inform and frame the research. The discussion in Section 4 explains how the notions of donating and benefiting communities yield insight into how political scaling justifies research, and the conclusion summarizes how social anthropology can contribute to studies in GE.

## 2. Political scaling: donating and benefiting communities

In GE units of analysis fulfil particular roles, whereby donating population communities play a main role as primary basis for data collection. Projects also have referent populations, which serve as units of comparison, over which data can be generalized. The outcome of GE studies can be used by governments in the formulation of public health policies or medicine or by companies to test and market their products. The communities that can benefit from the data collection in the initial 'donating communities' I refer to as 'benefiting communities'. Researchers usually match the roles and units of research in such a way that studies are compelling, valuable and have wide implications for wider communities. In this section, I will describe some mismatches between the ways donating and benefiting communities are presented in the TZL study. I will start with a description of how the TZL and affiliated researchers represent the project benefits for various populations, after which I do the same regarding the sample (donating) population.

### *2.1. Benefiting communities*

The TZL describes how the conditions of certain socio-genetic groups may improve, directly or indirectly, as a result of the outlined epidemiological research (Wang et al. 2009, 223). Whereas the main 'donating community' for TZL consists of inhabitants in and in the vicinity of Taizhou (Wang et al. 2009, 10), the benefits of the research lie in the statistical connections found between genetic propensity, lifestyle and environmental factors. Here, the statistical connections are presumed to lead to knowledge that will improve public health policies and security. This would raise the quality of the Chinese population in at least two ways: through the possibility of adjusting population behaviour, and by creating substantial savings on healthcare expenses. The TZL study, then, is justified as being beneficial to people with potential modern welfare diseases in Taizhou, including 'those who are overweight, play mahjong, enjoy delicacies, have sedentary lifestyles' and 'many other factors such as watching TV, using a mobile telephone and a microwave oven' (Wang et al. 2009, 10). However, it is also portrayed as important to the Asian population in general 'by examining chronic diseases that cannot be adequately investigated in studies conducted in Western populations' (Wang et al. 2009, 223, 6, see below). This suggests that the research of the Taizhou community could benefit all people with potential modern welfare diseases in Asia.

At the first sight, the scientists are very clear about the target of the longitudinal study: not the poor with communicable diseases or those who currently suffer from disease, but the 'general population' (Wang et al. 2009, 10), residing in urban areas with high living standards:

> The living standards of the general population are far higher than ever before. Dramatic transformations such as urbanization, aging, westernization of diet and lifestyle, pollution (air, water, soil), city noise, stress and tensions have simultaneously accompanied economic growth. (Wang et al. 2009)

While the burden from infectious diseases has gradually diminished, the burden from cardiovascular diseases, cancer, diabetes mellitus and other chronic diseases has increased substantially. This is a result of new, modern lifestyles:

> Enjoyment of delicacies and sedentary entertainment such as playing Mahjong and watching television are examples of activities which people spend time on during their leisure time in

> China, and which may lead to an increased risk of chronic diseases … Chronic, non-communicable diseases now account for an estimated 80% of total deaths and 70% of disability-adjusted life-years (DALYs) lost in China. (Wang et al. 2009)

The TZL aims to explore the environmental and genetic risk factors for cardiovascular disease, cerebral vascular disease and cancer. To the TZL, it is of crucial importance to know the relationship between lifestyle disease, genetic make-up and environment:

> About 48% and 26% of residents of Taizhou live in houses <300 m or 300–1000 m from main roads and factories, respectively. The influences of these environmental exposures, solely or in combination with genetic factors, on the prevalence of non-communicable chronic diseases require urgent evaluation. (Wang et al. 2009, 223, table reference omitted)

Although samples derive from the population of Taizhou – including some agricultural communities – the communities that benefit from this project, through the scientific generation of data, are the much wider general population. The latter are presented as the middle classes, which the study equates with the majority of the population in China. From a different angle, the population domain is seen not just as an epidemiologically interesting community limited to Taizhou and surroundings, but also as a genetic population:

> Taizhou is at the junction of north and south China and downstream of the Yangzi River (one of the two largest rivers in China) … Historically, the Taizhou population is a mixture of people from north and south China. Nevertheless, after establishment of the People's Republic of China in 1949, gene flow has been very limited. Taizhou is also well-known for a high prevalence of digestive cancer. (Wang et al. 2009; references omitted)

The authors seem to say that Taizhou both represents China, being a mixture of people from north and south, as well as a location with a specific genetic pattern acquired through limited gene flow. Fanqing Chen, advisor to the project, explains that:

> The location of Taizhou is a good location because it's in the middle of China. It's had migrants going in and out over long periods of time, so there has been a lot of genetic interaction. This makes it a very interesting case study for population genetics. (Anonymous 2007, 389)

One wonders how Taizhou can genetically represent China for such widely varying reasons, ranging from 'a limited gene flow' to 'a lot of genetic interaction'. Furthermore, according to Mr Chen, the project has the aim of 'becoming a valuable resource for Asian genome data currently not represented substantially elsewhere'. This, Mr Chen argues, 'should help pharmaceutical companies and researchers to develop 'personalized therapeutics' suitable for Asian populations' (Toland 2007). So here we find that it is not just the people from Taizhou or the people from China who are going to benefit from the banking project, but also Asian communities in general. The TZL claims to serve the interests of the wealthy middle classes, the general population, China and Asia as benefiting communities, thereby engaging in the political scaling of both its reach and relevance.

### 2.2. Donating communities

An important aspect for the justification of a project is whether the benefits can justify the burden of sampling a population. To be justifiable in the eyes of funders and local community representatives, preparations need to guarantee appropriate ethical review in

terms of international ethics standards, and it need to prove importance in terms that could persuade both funders and potential donors of the project's worth. The targeted donating communities of Taizhou, according to the project leaders, were approached with great care: preparations had been put in place for ethical review by the Institutional Review Board (IRB) of the university the researchers were affiliated with; information on the project was circulated through the mayor of Taizhou and the local propaganda department; interpreters fluent in the local languages were hired to talk to inhabitants; and the anonymization of data garnered from research participants was promised and guaranteed through secure banking procedures (Wang et al. 2009; interview J, K, July 2012).

The TZL, apart from providing physical samples, requires participants to undergo physical examination and respond to a large number of questions pertaining to private information and that of their families (interview J, K, July 2012). This requires the building of a good report and trust. The researchers succeeded. In the first phase of the TZL, about 100,000 adults aged 30–80 years were interviewed through questionnaires and samples of buccal mucosal cells. In phase II, fasting blood samples were collected for biochemical measurements (e.g. lipid, glucose, hepatic function, renal function) in half of the communities sampled in phase I. Phases I and II were to be followed by continuous monitoring of morbidity and mortality through a chronic disease register system, and follow-ups were to take place every three years. The project leaders explain that a roster of all persons aged 30–80 years was obtained from the offices of the Public Security Bureau, Bureau of Statistics and Community Committee. Three to seven days before the baseline survey, the study staff distributed advertising material to every household of the target community (Wang et al. 2009).

After obtaining written informed consent, a trained interviewer using a semi-structured questionnaire completed face-to-face interviews. Interviewers were natives who knew the dialect of Taizhou to ensure smooth communication with the participants (interview J, K, July 2012). The questionnaire covered socio-economic status, demographic characteristics, residential history, personal habits (e.g. cigarette smoking, alcohol consumption, drinking of tea and coffee), dietary habits (semi-quantitative food frequency questionnaire), family history of selected diseases, cognitive function, physical activity (over the past 5 years and during adolescence), medical history, and, for women, menstrual/reproductive history and use of hormone therapy. Lifetime occupational history was also obtained in the survey, including all jobs held for at least one year (Wang et al. 2009).

The project leaders expected that a racial component is critical to the question of how chronic diseases in modern wealthy communities in Western and Asian societies differ genetically:

> With years of follow-up, the TZL study will provide a valuable opportunity to test many important etiologic hypotheses for chronic diseases that cannot be adequately investigated in studies conducted in Western populations. (Wang et al. 2009, 223, 6)

The scientific results are expected to have significant implications for public health, social policies and genetic discrimination, which have all increased in importance over the last decade (Sui and Sleeboom-Faulkner 2015). The question arises, then, why ethical review for the project was conducted at a university that has a clear stake in the research: the research project provides both research and career opportunities to its members, besides being a potential source of lucrative earnings (interviews J, K, July 2012).

However, ethical approval was also obtained from the Chinese Board of Ethics. But considering that state policies regard genomics as an engine for modernization and economic growth, making the PRC a giant stakeholder, critical doubt can be cast on the ability of the national ethics committee to act independently (interview P, July 2012). Furthermore, as follow-up research takes place every three years, the declared anonymization of cohort-participants requires an independent body to manage the key to identification. But the independent body is the Taizhou Institute for Health Science, partly owned by the Taizhou government and partly by University X (interview J, K, July 2012). These conflicts of interests may be inevitable, but it raises the question if ethical review can be independent at all. This has implications for scientific policy-making and the public discussions on socio-genetic repositories in general, which is why an anthropological study sensitive to local history and stakeholder interests may be helpful.

## 3. Local, historical and national discourses underpinning TZL

How does political scaling come about? I suggest that in their research presentations, researchers strive maximize its benefits and minimize its harms, in their efforts to cater to their funders and collaborating communities, and draw on the discourses these communities are familiar with. Both the state and the international scientific community are crucial to the ability of researchers to conduct and publish research. In the design of projects and publications, notions of the Chinese nation and its socio-genetic make-up derive from the former, while 'international' notions of research ethics and professional research conduct are important reference points to both. To clarify political scaling it is important, then, to gain an understanding of the institutions the researchers are part of and depend on, and of the key concepts that are constitutive of their discourses. In this section, I will start with a characterization of the conditions that enable the TZL project. This characterization serves to identify the discourses that shape the definitions of the donating and benefiting communities that are core to the justification of the research.

### *3.1. The discursive embedding of the Taizhou study*

CMC is located some 170 km north of Shanghai in the heart of Taizhou and it occupies more than 25 $km^2$ of industrial land, where flashy high rise is dotted over this suburban flat area of Jiangsu province. CMC has been a major attraction for life science research and the pharmaceutical industry. Its sparkling infrastructure seems to scream 'welcome' to potential industrial investors: the convenience of the location is celebrated on billboards, flyers and the Internet, all lauding its closeness to major airports, its investment privileges and its full support from the local, provincial and national governments. In advertising leaflets, the city of Taizhou is flaunted as the fastest growing medical industry location in Jiangsu, with over 35% annual growth between 2005 and 2010. Established by the Chinese Government in 2005, CMC facilitated the development of a streamlined pharmaceutical and medical materials industry, concentrating all medical services and support in one location. The government's interest in Taizhou was not coincidental, as anyone in the district can tell you: Taizhou is the hometown of former President Hu Jintao (2002–2012) – and, mutual beneficial relations, have leaded joint-support for CMC

policies that tempt international pharmaceutical and medical equipment companies to locate in the City, including preferential tax benefits relative to other locations in China, expedited support services to help with registrations, patent filing and intellectual property protection (Advantage China Inc. 2011). Businesses located in CMC carry out a range of manufacturing and support services including research and development, creation and processing of medical materials, distribution, comprehensive healthcare delivery solutions and patent filing support.

The ambition of TZL's leaders shines no less: the group aspires to turn their collections into 'the best biobank of China' and hope for global recognition of their research. In its five-year plan, the Ministry of Science and Technology (MoST) has provided the financial means to develop procedures for making standard operating procedures to unite biobanking procedures in China. There are various advantages to the location of the biobank: its close distance from Shanghai, the infrastructural provisions and advantageous conditions described above, but also the ideologically supportive attitude of the local population. The Mayor of Taizhou was the first to support the sampling of the population and the first to participate in the research, making the project's recruitment and advertising – using the local Propaganda Department of the local CCP – much easier than it otherwise would have been (Interview F, July 2012). Although it received financial support and benefits from CMC's special policies, and project funding from MoST, the biobank was eventually expected to become financially independent. While it received funding for its building, was built to allow for special corridors to accommodate President Hu Jintao and his security entourage – who was scheduled to visit – it has to negotiate with hospitals and universities to exchange samples and services to become economically viable and sustainable (interview J, April 2009).

The Taizhou project prides itself on conforming to international standards of science, banking practices and bioethics. As the researchers see their work partly as preparation for further, large-scale research, they are aware that the research ethics involved in the data gathering and processing will be of crucial importance (interview F, July 2012). Compared to the initial ambitious sampling plan of one million, targets have become more modest. In 2012, the project had 140,000 samples, and aimed for 200,000 within two years (Interview F, July 2012). Its scientific ambitions, however, are still high. The collaboration with University X and the aspired national-scale bank form the basis for 'world-class epidemiological research into Chinese population health' (Interview F, July 2012). This, the leaders of the project, who have had much experience in the United States, requires research methods and ethical procedures of an international calibre. For despite its state support and the close relations with institutions in Shanghai, the Taizhou biobank is expected to earn its keep by means of competition, negotiation and exchanges. And it is this precarious situation, which requires TZL's leadership to present its longitudinal cohort study in terms that accommodate the different demands and ideas of the various communities it collaborates with. In other words, indebtedness, dependence and the need to compete entail the adoption of a research and writing style that embody notions belonging to the various discourses. Only in these terms one can understand the meaning of minimal burden to donating communities and maximal burden to the wider communities, that is, political scaling.

### 3.2. Zhonghua state discourses and socio-genetic identities

Chinese national identities have been formed through various biological and material ideologies, and more recently through confrontations with commercial biotechnologies, which underpin the formation of 'new emotional maps of belonging and collective fate, keying ordinary folks to the scientific and security stakes of being both 'Asian' and modern' (Ong and Chen 2010). These imaginings of biotechnology are framed by older state discourses. Heavily influenced by policy-makers and elite academics, notions of culture, ethnicity and race have been conflated throughout the twentieth century (Dikötter 1992, 1997; Sleeboom-Faulkner 2002). This conflation of the cultural and the biological has also been salient in dominant discourse since the 1980s, when Chinese 'Zhonghua' identity was discursively based on ideas of Chinese racial homogeneity, Socialism with Chinese characteristics, Zhonghua history, Confucian cultural unity and China's genetic diversity. The idea of Zhonghua's genetic diversity, including all of the PRC's 56 ethnic nationalities, is seen as an important asset to China's potential, a sign of evolutionary strength (Li 1990; Sleeboom-Faulkner 2002; Hu 1987, 77; Su 1994).

In the 1990s, Chinese peoples' genetic resources became both a source of worry and of missed opportunity to health security, pharmaceutical exploitation and scientific progress. In 1996, US media revealed that a drug research programme involving Harvard University researchers and a company called Millennium tasked six Chinese medical centres with sampling the blood and genes of 200 million Chinese people (Pomfret and Nelson 2000; Sleeboom-Faulkner 2005). Soon, financial details about a Millennium–Harvard deal in Anhui province was leaked to the Chinese press and caused a storm of criticism. The idea of 'US capitalists' profiting from China's genetic heritage sparked such fury that foreign genetic research was stalled for a year (Pomfret and Nelson 2000). The State Science and Technology Commission promptly formulated draft regulations for the collection, handling and export of genetic material in the *Interim Measures for the Administration of Human Genetic Resources*, promulgated by the General Office of the State Council upon its approval on 10 June 1998 (MoST 1998). The regulations made it very clear that genetic resources were not to be taken abroad without permission and observing due procedures as defined in the Interim Measures. In this spirit, other efforts by Beijing Genome Institute (BGI) with support from the Chinese Academy of Sciences to undertake the sequencing of 1% of the human genome in 1999 became a great source of national pride, as did BGI's first sequencing of the Asian (Chinese) genome in 2008 (Wang et al. 2008, 989). Similarly, the establishment of the Kunming ethnic DNA bank in 2006 did not just represent efforts to facilitate scientific research; it also expressed the wish to protect China's national genetic heritage and faith in China's future ability to become a dominant player at the forefront of global developments in the life sciences and the pharmaceutical industry (Sleeboom-Faulkner 2005).

Any research on GE that is in agreement with dominant discourses, then, needs to indicate how it values Chinese genetic resources, defines it in these terms and show how it benefits them. Research ethics, here, in the first place means not to waste Chinese genetic resources, and second, to adhere to national standards of bioethics. Crucial to scientific acknowledgement in international circles and advancement among international competitors, however, is catering to standards for research ethics and professionalism.

### 3.3. International competition and discourses of health and biosecurity

Notions of national health and national security place great emphasis on the importance of GE, as it involves crucial knowledge about genetic differences at home and in an international context. It has led to an expansion of the social jurisdiction of life scientists, whose views are being incorporated in the formulation of health security (Elbe 2010). In China, notions of global biosecurity have led to worries that China has fallen behind global developments in the life sciences, leaving China's genetic community unprotected. In 2002, the *China Production Daily* claimed that all Zhonghua Chinese stemming from the Yellow River Basin share a similar genetic make-up, and because of its high quality – due to medical naivety and low pollution levels – were targeted for genetic experimentation (Anonymous 2002). Human experiments were conducted, not only on the DNA of the Han and the Tibetans, but also on the differences between Eastern and Western genetic codes. Another article in *Beijing Youth* (*Beijing Qingnian Bao*), entitled 'We will start to research the characteristics of the national/ethnic disease gene' (Anonymous 2000), foresaw that foreign companies would steal Chinese genetic blueprints to produce medicine and sell it to the Chinese for a high price, because the different sequence in amino acids between, say, Germans and Chinese, would make medicine effective only in some races (Anonymous 2000).

In debates about China's genomics, genetic knowledge is not only crucial to biosecurity, but also to national health security. Critical attitudes towards foreign genetic exploitation of Chinese medically and bioethically naïve populations (Yang 2003) are also expressed in the way genomics has become an issue of biosecurity. Thus, in 2000, a genetic research centre in Beijing applied for government funding to finance a 'Chinese Genetic Multiple Condition Plan' (Fang 2001). Its explanation included references to foreign military biological weapons attacks on the Chinese race. Newspapers displayed a similar concern about biosecurity. One article in *China Production Daily* claimed that genetic engineering is used to make ethnic-specific biological weapons (Anonymous 2002). The article intimated that Sino-American joint research projects in the 1990s used students and joint research to steal Chinese blood and to decode the DNA of the Chinese race, providing information on the Chinese immune system which could be used to create genetic weapons. For this reason, it argued, China must rapidly develop this technology by joint research, and at the same time alert people to preserve state and ethnic security.

It is clear, then, that there is a racial and health component to biosecurity. The biological robustness of the Chinese people, the maximization of health through public health policies, and China's pharmacogenomic utilization of the particular Chinese and Asian genetic make-up are issues of vital interest to China's political leaders and scientists. And it is this discourse of health and biosecurity which underlies research funding and GE research as reflected in the political scaling in the TZL.

## 4. Discussion: political scaling, discourses and TZL

An examination of Chinese history, identity and international policies show how discourses around the Zhonghua state, health and biosecurity condition the formulation of GE studies, but catering to the wishes of funders and international scientists has led to discrepancies. I will first discuss this political scaling in terms of the scaling of relevance,

reach and ethics, before relating it to the conditions and discourses in which TZL functions.

Describing the rationale of TZL, project leaders use particular ways to present the donating and benefiting communities and the measurements and methods with which they indicate how their research contributes to genomics, medicine, epidemiology and population genetics, and conform to ethical standards. In their work, authors zoom into communities of diverse geographical scales and kinds, which function as units of analysis appropriate to their research questions. In some cases, the zooming into these communities happens in such a way that the reach of the study seems to be out of proportion compared to the sample population. Thus, the sample population, limited to individuals in Taizhou and environs, generated data, which were indicated to be relevant to much larger population units, such as China and Asia without much scientific justification. This practice raises questions about the scaling of relevance, reach and ethics.

The *scaling of relevance* refers to the way a GE study claims to be relevant in addressing the problems of communities. During recruitment in Taizhou, the TZL was advertised as leading to valuable knowledge that would take China's science onto a higher level, increase China's insight into its human genetic resources, and enable understandings that would improve China's healthcare. But TZL claims about the need for research and investments for non-communicable diseases – rather than infectious diseases – are based on standards created in wealthy countries, as are the socio-economic indicators of lifestyle, income, modernity and environment. Even though it is not the responsibility of GE to deliver healthcare, the capacity of delivering the healthcare and drugs that result from the research is so low that the study cannot be justified in terms of public health value. Using the local language (Taizhou dialect), mobilizing local government departments, and presuming upon notions of patriotism and scientific progress this message was received positively. Thus, the scaling of relevance in combination with other activities can persuade communities that they benefit from research participation, and it can lead to research support in terms of funding, investment, sample donation, research/ethics permissions, scientific validity and scientific collaborations.

The *scaling of reach* refers to the ways in which banked epidemiological data from a 'donating community' are claimed to be generalizable, and therefore useful, to a wider 'benefiting community'. In the presentation of the rationale of the TZL in Section 2, we saw how donating and benefiting communities were formulated using administrative–geographic units of Asia, China, Central China and Taizhou. They were also formulated as genetic units, and as population units associated with health standards and socio-economic levels. The definitions of these units contain various biases: first, the way geographical units are naively defined as state-political and administrative givens. Authors do not clarify that politico-geographic units are developed through politico-economic processes of nation-state building and may have political implications for local political views, policies and propaganda. Second, the choice of the politico-geographic units of China, Asia, Taizhou and Central China was justified in genetic terms. This is odd, as the genetic research was yet to take place. In addition, diverging standards of genetic homogeneity were applied, e.g. in the case of internal migration both the homogeneity and admixture of the population are provided as reasons for conducting research in Taizhou. The genetic characterization of the people of Taizhou in relation to large and variable geographical units such as China and Asia requires scientific demonstration and cannot be assumed.

The *scaling of ethics* refers to the claimed appropriateness of ethical review procedures of one location for a study in another. Although the dominance of international standards of research ethics and the pressure on scientists to apply them regardless of their situation and local medical and research capacity is reprehensible, the authors' claim of following international ethical standards is misplaced. But the authors' scaling of ethical review, using permission from institutions belonging to benefiting communities, showed a mismatch indicative of overlapping interests between researchers and IRB.

By becoming more familiar with the conditions and structural dependencies of the TZL, it became clear that research much depends on state support and acknowledgement from the international scientific community (Section 3). Researchers rely largely on patriotic discourses and Enlightenment ideologies of progress when persuading Taizhou populations to participate in their research. Thus, Huang Jinlin, the CEO of Berkeley Biotech, suggested that local people regard participation in this project 'as a public service', believing their donation serves the progress of the nation-state. Describing the lack of worry among the population, BBC reporter Toland stated, 'Blissfully unaware of controversies about privacy and confidentiality, Taizhou citizens continue spitting into cups in the name of science' (Toland 2007). TZL research also uses faith in science when it speculates that knowledge of lifestyle and environment could pave the way to prevention rather than to curing disease through limited health and research budgets: public health advice on lifestyle, insight into genetic vulnerabilities to drugs, employment, food and environment, and knowledge of the detrimental effect of the living and work environment on population health would replace healthcare spending through proactive public health measures (interview J, 2012).

The presentation of the research has to show adherence to the highest standards of ethics used by the international science community, as the biobank has ambitious plans. A main purpose for scientists, including those involved in the TZL, is to conduct research that leads to international publications, recognition, funding and patents. Thus, Wang Wei, dean of the School of Public Health and Family Medicine at Beijing's Capital Medical University, asserts that the biobank is important for the development of China's infrastructure for scientific research, commenting:

> These facilities will give Chinese scientists a good position to collaborate with overseas scientists. (Toland 2007)

The plan is for pharmaceutical companies to take advantage of China's expanding healthcare market to use the database to tailor drugs to suit Chinese consumers. As the government pressures scientists to attract private investment, many principle investigators wear both academic and commercial hats, as scientific leaders and as company directors. The advantage of standing on 'two legs' is obvious to Fanqing Chen, a scientist from Lawrence Berkeley National Laboratory and adviser to the project. Chen explains that 'genetic testing provides personalized medicine, or the ability to predict a response to a drug, either positive or negative, depending on genetic background' (Toland 2007). A better understanding of disease biomarkers, indicators for diagnosis, treatment guidance and prognosis would clearly help pharmaceutical industry to develop products for the Chinese market.

This link with international pharmaceutical industry and the international science community requires the TZL to be of international relevance and conform to international banking and ethical standards. This is why TZL is disposed to relate its findings on

a selection of people in Taizhou and their lifestyles and the genetic population of the PRC, and even Asia. The political scaling here persuades readers and funders that TZL's GE study provides the international science community with valuable knowledge about China, Asia, and, by extension, the world. The study would yield research outcomes about how Asians/Chinese/modern society/Taizhou people have specific healthcare needs (drugs, public health, insurance, life style advice, biosecurity), even though these needs are defined in an abstract manner and are unlikely to benefit the indicated 'benefiting communities' of Taizhou, who carry the brunt of risk associated with sample donation.

## 5. Conclusion

This article set out to understand how political scaling in GE research means that research is justified by speculation on the relevance of data on a relatively small sample population to much wider populations, or overgeneralization. Political scaling constitutes a mismatch of scales: when the relevance, reach and research ethics of a study in GE loses sight of how the study links sample donating and benefiting communities. Political scaling can occur intentionally – to garner financial or political support for a project – or unintentionally, when misrepresentation slips in through political discourses used by the institutions upon which a study depends. In the case of TZL, the GE study is largely supported by state institutions and justified in terms of state policies. However, it is also dependent on international scientific discourses through which it gains international recognition.

As overgeneralization implies misrepresentation, it can damage the study's credibility. And as political scaling in GE can have important consequences for political decision-making in areas ranging from public health and science policies to biosecurity and biobanking, it is important to prevent both its intended and unintended forms. Anthropological fieldwork can play a complementary role to GE by examining the particular discourses a project is part of. It can do so in various ways. *First*, by identifying forms of political scaling and redefining the study in terms of donating and benefiting communities such study could identify discrepancies between the investment and yields of a study in terms of socio-political and cultural acceptability. *Second*, anthropological fieldwork can shed light on the institutional relations of dependence relevant to the project and determine how these dependencies translate into collaborative arrangements. This can provide an indication of the kinds of discourses to which a project needs to respond. *Third*, archival and web study (newspaper, Internet, and articles, government documents) can provide insight into the discourses of institutions the project is part of or dependent on, clarifying the conceptualization of a project and the claims and justifications it makes related to research populations and methods. Fourth, anthropologists can help to make suggestions to formulate the project design so that definitions of the donating and benefiting communities are defined in a way that is transparent and acceptable to, not just the funding institutions and the science community, but also to the donating community.

This case study aimed to provide an example of such a study. First, it identified political scaling by redefining the justification of TZL in terms of donating and benefiting communities through the following observations:

- The local geography of the sample population is defined in in vague genetic and contradictory terms.

- Administrative units are interpreted as natural communities with homogeneous populations.
- The sample (donating) population of Taizhou and environment were defined in such a way that it seems representative for China and Asia.
- Communities serving as units of analysis were defined from various perspectives (e.g. social, genetic, cultural, health) so that it was hard to see how they relate to each other, and to communities on different scales.

Second, anthropological fieldwork probed into the environment and conditions of the project, showing that:

- The location of the sample population is an industrial park with political links to the state.
- Donor/sample recruitment happens with the help of those that invest in the project (local government).
- The database is used on a commercial basis (pharmaceutical industry) and for scientific purposes (international science community).
- The project's ambition is to grow into a national database and has close international scientific and commercial links (government, other research institutions, international scientific community).

This explains why:

- Ethical standards for the project are adopted from abroad.
- The ethics committees belong to institutions that support the project.
- Ethical oversight is organized in communities without open public deliberation.
- Scientific knowledge claims promise medical solutions not accessible to donating communities in the foreseeable future.

Third, archival and web study (newspaper, Internet, and articles, government documents) provided insight into the discourses of relevant state and international institutions, which clarify how the project justifies its self through its knowledge claims and design. Thus, state discourses attach great value to genetic identity, regards the genetic make-up of its people as important to its national security and as a resource for conducting science, history and public health. The Taizhou bank is of national importance to China in several ways: for public health purposes, for reasons of biosecurity, and for its biocultural identity. This framing conditioned the way in which the Taizhou study was formulated.

Fourth, by making the discrepancies, dependencies and discourses explicit, donating communities may be presented with various perspectives on their role in a GE study. Such efforts should validate its relevance to public health, inform the recruitment of study participants, identify conflicts of interests, enrich studies of GE, and suggest ways of reformulating study designs. As GE strives to achieve a solidity of scientific claims made about the relevance of local data to large populations, and as an important aim of medical anthropology is to understand factors that influence health and well-being, and the experience and distribution of illness, such complementary role could enrich both disciplines.

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Research for this article was approved by the research ethics committee of the University of Sussex (1011/03/03; 1011/09/09).

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